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From the Editors' Desk: Confronting Costs of Care at the End of Life

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Most experts agree that the current rate of rise of health care costs is unsustainable. The good news, however, is that there is an emerging consensus among policymakers over what needs to be done: realign financial incentives; reinvigorate primary care; support more informed, patient-centered decision making; develop a more robust evidence base of comparative effectiveness; create standards for electronic health records; invest in public health. In addition, many feel that excessive tests, consultations, and procedures in the last year of life contribute not only to higher costs but to diminished quality of care. However, these concerns were caricatured by conservative pundits and politicians, who portrayed hospital ethics boards as "death panels" and ultimately ensured that end-of life care was exiled from the health care reform agenda.

Why focus on the end of life? Because about one-quarter of Medicare spending occurs during the last year of life, because there is considerable geographic variation in this spending, and perhaps because, as Princeton bioethicist Peter Singer has pointed out, most dying patients are elderly, and a slowing or reversal of illness in an 85-year-old saves fewer life-years and therefore produces less social utility than the same slowing or reversal in a 35-year-old. (Readers interested in the debate over utilitarian versus categorical ethics might like Michael Sandel's popular Harvard course, found at http://www.justiceharvard.org/).

In this month's issue of *JGIM*, several articles deal with the care of patients who have serious medical conditions and who may be nearing the end of life. In her *Text and Context* column, Roslyn Weaver provides a touchstone for teaching the principles of clear communication, building safe and reliable systems, and breaking bad news. As Weaver explains, Dr. Trent, a principal character in LM Montgomery's *The Blue Castle*, mistakenly writes to his patient Valancy Stirling telling her she has a fatal disease; paradoxically this frees her to explore the more adventuresome side of her nature. Not knowing this, Trent feels awful about the possible effects of his error on Valancy, but shrugs off the miscommunication to the other patient involved in the miscue, Jane Sterling. She remains blissfully unaware of her terminal diagnosis through the moment of her death two months later.

Blissful ignorance may be one of the reasons most patients with terminal illness do not enroll in hospice early enough to gain the full benefits. The spectrum of reasons is explored systematically in an article by Vig et al., who report that some reject opportunities to enroll in hospice because families believe the patient "is not ready," because patients fear enrolling in hospice will close off other treatment options, and because of concerns about disrupting continuity with their current provider. Their inquiry does not stop with patients and families, though. By sharing patient and family concerns with hospice staff and end-of-life experts, the authors construct a set of practical recommendations for helping patients make fully informed decisions about end-of-life care.

Anyone who makes ward rounds knows there is no sorrier situation than the patient facing serious or terminal illness alone, bereft of family and friends. When the patient is demented, delirious, or otherwise incompetent, the ethical tensions intensify even as the terribleness of the situation eases. When a patient cannot make decisions for him or herself and has no ready surrogate, a guardian is appointed by the courts. Bandy et al. describe the process of medical decision making for incapacitated, hospitalized adults for whom court-appointed guardians are requested. They find, not surprisingly, that the legalistic structure erected to solve a social problem has holes; many important medical decisions are made while patients await appointment of a guardian.

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